

WAKE-UP CALL

FROM THE AMERICAN SLEEP APNEA ASSOCIATION

FALL 2009

ASAA A.W.A.K.E. NETWORK NEWS

The **A.W.A.K.E. Network**, with more than 300 local meetings, gained its first **virtual A.W.A.K.E. meeting** in September as 60-odd truckers and others scattered across the country gathered by telephone to discuss how they manage their sleep apnea. The principal speaker was Mark Berger, M.D., Houston, TX, a pulmonologist and president of Precision Pulmonary Diagnostics, who specializes in treating truck drivers. He was joined by Edward Grandi, Executive Director of the American Sleep Apnea Association, and John McElligott, M.D., Knoxville, TN, the founder of Professional Drivers Medical Depots. The meeting was coordinated by trucker Bob Stanton on behalf of the A.W.A.K.E. network and Gary Hall for Truckers for a Cause. Participants joined in by telephoning to a conference call service at 7 p.m. Central Daylight Time and keying in an access code. Their only cost was the cost of the phone call ... Endocrinologist Joseph Barrera, M.D., spoke about type 2 diabetes to 20 participants in the **Mission Sleep Disorders Institute A.W.A.K.E. group**, Mission Viejo, CA, in July. Most of the audience acknowledged that they had not previously been aware of the association of sleep apnea, diabetes, insulin resistance, and heart disease. As a result, Barrera's talk stirred an unusually strong response ... During an August gathering, psychiatrist Salvador Sanches, M.D., told the **Quincy Regional Sleep Disorders Support Group** at Blessing Hospital Sleep Center, Quincy, IL, about how sleep can affect your mental health and how your mental health and the psychiatric drugs you take can affect your sleep. Sanchez is on the staff of Blessing Behavioral Center, the hospital's psychiatric unit.

A.W.A.K.E. - ALERT, WELL, AND KEEPING ENERGETIC

THERE IS MORE THAN ONE APNEA For Central Sleep Apnea, CPAP Is Often Not Enough

Most discussions of sleep apnea focus on obstructive sleep apnea and its treatment. Sleep apneas, however, come in more than one form.

The sleeper who suffers from obstructive sleep apnea periodically struggles to breathe but is unable to inhale effectively because his or her airway has collapsed. The sleeper whose problem is central sleep apnea periodically doesn't breathe at all, or breathes so shallowly that oxygen intake is ineffectual. In either type of sleep apnea, the lack of oxygen usually causes the patient to wake up, at least briefly.

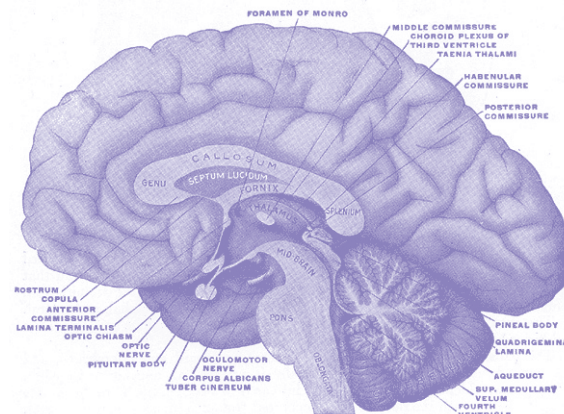
To put it another way, the OSA patient has a mechanical problem, one that almost always can be corrected by a continuous positive airway pressure device. Treatment of the CSA patient is more challenging because the signal to the body to inhale is not being transmitted from the breathing center in the brain.

Sleep experts report that the great majority of central apnea patients also experience obstructive sleep apnea although the CSA may not be noted until the OSA is treated. In some cases the sleeping CSA patient displays not a periodic failure to breathe at all but a periodic shallow breathing or underbreathing that alternates with deep overbreathing,

a condition known as Cheyne-Stokes breathing. Estimates vary as to the frequency of central sleep apnea. Some say it accounts for 20 percent of all cases of sleep apnea. Michael Coppola, M.D., a pulmonary, critical care and sleep disorders physician in Springfield, MA, who is a member of the American Sleep Apnea Association Board of Directors, questions that number.

"I don't think it's 20 percent," he said in a recent interview, "but it's significant."

The symptoms of central sleep apnea are for the most part the same as those of obstructive



Wikimedia Commons/Lithograph from Gray's Anatomy

In this drawing of a cross section of a human brain, the brainstem—the area that controls breathing—is the light gray segment at the bottom that looks like a turkey's head. It's the top end of the spinal cord.

sleep apnea. They include chronic fatigue, daytime sleepiness, morning headaches and restless sleep. But if the cause is a neurological disease, the CSA sufferer may also experience difficulty swallowing, voice changes, and an overall sense of weakness and numbness. A thorough sleep study with polysomnography will show whether the lapses in breathing result from airway blockage or irregular breathe signals from the brain.

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CSA frequently occurs among people who are seriously ill from other causes: chronic heart failure; diseases of and injuries to the brainstem, which controls breathing; Parkinson's disease; stroke; kidney failure; even severe arthritis. It is seen among users of opiates. And there is idiopathic CSA, which simply means the cause is unknown. "For idiopathic apnea, the outlook is generally favorable," notes Medline Plus, an online information service of the National Institutes of Health.

An online discussion of central sleep apnea prepared by experts at Minnesota's Mayo Clinic breaks the disease down into five types:

1) Primary CSA, which is the same as idiopathic CSA—the patient has no known related diseases.

2) Cheyne-Stokes breathing CSA, which may be a product of heart failure, stroke, or possible kidney failure.

3) Non-CSB CSA associated with other medical conditions, including heart and kidney problems.

4) High-altitude CSA, which often appears during sleep at altitudes above 15,000 feet, and induces a form of Cheyne-Stokes breathing with noticeably shorter cycles than classical CSB.

5) CSA induced by the use of certain drugs, typically opiates.

Type 4 usually disappears when the patient descends to lower altitudes, and type 5 is best treated by alteration of the drug regimen, the Mayo article said.

Unfortunately, when CSA is a byproduct of some other disease, the outlook tends to be more discouraging, according to Medline Plus. Treatment of these complex varieties of CSA generally call for aggressive treatment of the accompanying condition by another medical specialist, for example, a cardiologist in the case of heart failure.

"Central patients are more challenging," said Coppola. "The hard part of people going back and forth requires careful coordination between the breathing physician and the heart care specialist. It's critical that the sleep doctor coordinate with the cardiologist."

He paused, then added, "Unfortunately sleep medicine is often practiced in a tunnel."

In some cases effective treatment of the accompanying illness, if there is one, reduces or eliminates the CSA, but there are often treatments that the sleep physician can pursue in tandem. In cases where CSA is

A LETTER FROM EXECUTIVE DIRECTOR EDWARD GRANDI



With this issue *Wake-up Call* wraps up five full years of publication under my leadership. When I became executive director of the American Sleep Apnea Association

I immediately recognized the importance of a regularly appearing newsletter for getting useful information out to our members. Your membership dues make this publication possible. Thank you.

The coming year promises to be momentous for ASAA. In 2010 we celebrate 20 years of providing a unique service to the nation and, through the Internet, to some extent the world. We are the organization that people turn to for unbiased and clear information on diagnosis and treatment of sleep apnea. Our network of support groups known as A.W.A.K.E. (Alert, Well, And Keeping Energetic), now numbering

associated with heart failure, the patient sometimes has slow blood flow as well as erratic breathing and consequently is awakened frequently by a sheer lack of oxygen, Coppola noted. "You can't fix that with CPAP, but oxygen therapy usually helps," he said.

Aside from those patients, about half of those suffering from CSA can be managed on CPAP alone, Coppola said. In others, he continued, the CSA patient may

"Unfortunately sleep medicine is often practiced in a tunnel," Coppola said.

be assisted by a device known as adaptive servo-ventilator, which monitors the patient's breathing and kicks in with extra pressure when the normal respiration pattern breaks down. Some patients are helped by unvented CPAP masks, which tend to raise the level of retained carbon

more than 300, are lifelines to many who are struggling to adjust to therapy.

We are celebrating! I hope you will celebrate with us. Write to your local leadership, state government and member of Congress asking them to recognize the American Sleep Apnea Association during the month of March for the work it has done the past two decades. Remember, Sleep Apnea Awareness Day is Thursday, March 11, 2010.

Please consider making a special end of the year gift to the American Sleep Apnea Association. A gift of \$20 or more will help ensure the association will be here to help those in need for another 20 economically for everyone, including the ASAA, but as it draws to a close we can begin to see the light to a brighter future. The continuing generosity of our members has much to do with that brightening, and I am deeply grateful.

—Edward Grandi

dioxide in the blood. This in turn raises the blood's acidity and that tends to damp down overbreathing. The elimination of overbreathing discourages the shallow underbreathing that typically follows in Cheyne-Stokes breathing.

The effect of using an unvented mask is much the same as the effect of breathing into a paper bag, a homespun way of slowing overbreathing, or hyperventilation, as it is technically known.

Rahul K. Kakkar, M.D., director of the Sleep Disorders Center of the North Florida-South Georgia Veterans Affairs Health System, writes in an article published online earlier this year by emedicine. medscape.com that two drugs are sometimes effective in the treatment of CSA: acetazolamide (Diamox) and theophylline (Theo-dur). But he also notes that in certain situations the best treatment of central sleep apnea is nothing at all.

"If the [CSA] patient is not symptomatic, observation may be the only appropriate step. This may be the case in patients who have central sleep apnea during sleep-wake transition, patients without significant oxygen desaturation, or those who experience central sleep apnea during continuous PAP (CPAP) treatment of obstructive sleep apnea," he wrote. ■

ASK THE DOCTOR

Q I am symptom-free now after using the CPAP. Can I stop CPAP? How long will I have to use it?

A It will be a serious mistake for you to stop using the CPAP because you are symptom-free. The purpose of CPAP is to prevent obstruction in the back of your throat so that you can breathe normally, and in a way it is a symptomatic and not a curative treatment. Therefore, if you stop using CPAP, all your breathing problems will recur and you will begin to have symptoms along with all the adverse short- and long-term consequences. Sleep apnea is a lifelong condition like diabetes mellitus. Therefore, you have to continue to use the CPAP for your sleep apnea, just like a diabetic patient needs to use anti-diabetic medication or insulin injections indefinitely.

Adapted from Questions & Answers About Sleep Apnea, by Sudhansu Chokroverty, M.D., F.R.C..P., F.A.C.P. (Jones and Bartlett Publishers, 2008).

NEWS FROM WASHINGTON

As this issue of *Wake-up Call* went to press, Senate Democratic leaders were poised to open debate on their version of a health care reform bill. Still ahead was merging whatever might pass the Senate with the bill adopted by the House of Representatives.

The American Sleep Apnea Association continues to work with the Partnership to Fight Chronic Disease to promote five principles for meaningful changes in health care. In the view of the Partnership, these are the essential steps to effective reform:

- Development of “next generation” strategies to prevent, intervene early, and manage chronic disease.
- Promotion of healthy lifestyles and sound disease prevention and management in all sectors of the country.
- Encouragement of steady advances in clinical practice and research that lead

to improved quality of care for those with costly chronic diseases.

- Major advances in the quality and availability of health information technology throughout the health care system.
- Removal of barriers to good health so there are fewer health disparities.

In its publicity materials, the Partnership emphasizes that rising rates of chronic disease are the primary cause of excess death and disability in the United States and the largest factor in the increase of health care spending. Members of the Partnership are convinced that the only way to improve general health and to reduce the cost of health care is the enactment of reforms that change fundamentally the way the U.S. health care system “helps Americans prevent, treat, and manage chronic disease.”

The treatment of chronic disease consumes 75 percent of what is spent on health care, 83 percent of what is spent by Medicaid and a stunning 98 percent of what is spent by Medicare, according to figures assembled by the Partnership. In the light of those numbers, the potential savings to be achieved by more effective prevention of chronic disease is obvious.

If you have a connection to a member of Congress, please be in touch with Ed Grandi, the ASAA’s executive director. The potential legislation is currently at a stage where it is crucial that the voices of patients and medical specialists be heard.

At this writing, it appears that Senate Democratic leaders have decided to abandon the search for Republican support beyond the possible vote of Sen Olympia Snowe of Maine, and push through the bill with Democratic votes alone. That means shaping the bill to the liking of the three most hesitant Democratic senators, Mary Landrieu of Louisiana, Blanche Lincoln of Arkansas, and Ben Nelson of Nebraska.

If the bill is to survive Republican-mounted filibusters, and if Snowe votes with the Democrats, the Democratic leadership must have the votes of at least two of the waverers to garner the 60 votes necessary to end debate.

The three appear to be most concerned by the cost of health care reform, although the bill before the Senate is declared to be significantly less costly than the version already adopted by the House of Representatives. Those defending the cause of chronic disease need to be able to show why better care of chronic illness is cheaper in the long run. ■

ASAA IN BRIEF

The ASAA is collaborating in the launch of an online medical history taker that “thinks.”

Working with Edmund Messina, M.D., an East Lansing, MI, neurologist, and his Arbor Medicus global medical community, the Association can now offer sleep apnea patients and their physicians a free service through which the patients can update and refine their individual medical histories on a continuing basis.

Check out the service by opening the Internet Explorer browser on your computer and go to www.historytaker.org. (For now, the history taker works only on Explorer.) After registering and being provided an anonymous user name and password, you will be led to an interactive questionnaire with video accompaniment that continuously adapts itself to the answers you have provided, probing for additional details each time an answer suggests the need for further information.

Since each “node,” as Messina terms them, that is, each question-and-answer unit, can lead in differing directions depending on whether the patient answers “yes” or “no,” thousands of variations in the shape of a completed questionnaire are possible.

In addition, the history updates itself so that on a return visit the patient will be asked if he or she followed up on the physician’s suggestions based on the patient’s earlier responses and how symptoms have altered over time.

Messina likens the work of FloBase, the artificial intelligence he and colleagues developed that drives the history taker, to a “three-dimensional algorithm.”

Your physician, who can gain access to your history only with your authorization, gets an even richer portion than you, for the physician’s version includes a discussion of what might be inferred from your answers. That is, it raises questions for the physician and lists possible courses of action arising from the information you provided. Messina noted that Arbor Medicus needs to be very cautious about the language used in this dialogue with the physician lest the process be seen as making a diagnosis, which could be construed as practicing medicine without a license.

Whatever language is used, however, the history taken in the process is far more thorough than what’s possible for any but the rarest physician as he or she talks to the patient face to face. ■